Testimony of Lee-Anna Otis to the Public Health Committee regarding *House Bill 6263, An Act Requiring The Administration Of A Screening Test For Cystic Fibrosis To Newborn Infants*

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Senator Harris, Representative Ritter, members of the Public Health Committee: Thank you for giving me the opportunity to speak to you today about *House Bill 6263, An Act Requiring The Administration Of A Screening Test For Cystic Fibrosis To Newborn Infants*. On May 16, 2004 I gave birth to my first child, Colby. During my stay at the hospital, the doctor's noticed that his stomach was swollen and he had not had a bowel movement. My husband and I were informed that they were going to take him for some tests. A couple hours later, my husband came to my recovery room with a swollen face and red eyes, followed by the doctors. They sat down and explained to me that there was a good possibility that my son had Cystic Fibrosis (CF) because he had meconuim illius, which is a common red flag for CF. We did not know anything about CF and we were really scared. What was it? Is he going to die? What is his life going to be like? They also informed us that if the current treatments he was receiving to clear the blockage did not work, he would have to have surgery. We were devastated.

They brought him back from Children's to the NICU where I was able to stay by his side. He still had not had a bowel movement and his intestines were getting worse. I was discharged from the hospital but in no way leaving. They accommodated me and allowed me to stay in a room on the NICU floor where I remained by Colby's side the entire time of his extended stay. I could not hold him or feed him. I could just hold his little hand and talk to him. It was heart wrenching.

The day of his surgery, I had gone to my room to get an hour or so of sleep when I received a phone call from the NICU nurses. I ran down to find out what the issue was, fearing something bad had developed. They were holding a soiled diaper in the air and I suddenly started to cry the hardest I have ever cried in my life. We were all jumping and celebrating. The blockage had been cleared with the many efforts of the doctors, avoiding surgery. He started to improve and about three days later, I was able to feed him again and hold him. The next day he was able to come home. His extended stay was approximately 6 days.

Approximately a week or so after we brought him home, we got the devastating news that the sweat test confirmed that he indeed had Cystic Fibrosis. We were then contacted by CCMC and scheduled to come in and meet with the CF staff to talk about the disease, treatment, requirements, and to answer any questions we may have had. I had many.

Colby is now 4.5 yrs old. He is doing extremely well. The treatment plan he has been on since day one has been a God sent. Not to say he has not had any set backs, but with the early diagnosis he has been able to thrive unlike I had ever expected. I thank God everyday for the blockage in his intestines, because I feel that if he did not have that, we never would have found out he had CF until later. He would have went on to have

numerous problems without the proper treatment allowing irreversible damage to his lungs, among other things. Although he was diagnosed with pseudomonas in 2005-2006, a common bacteria that is very resistant to antibiotics and common problem for people with CF, his early diagnosis at birth allowed him to get the proper antibiotics/treatment and he beat the pseudomonas. That is a huge accomplishment. I owe it to his early diagnosis and intervention.

Colby continues to do well. He has never been admitted into the hospital for any problems as of yet. He has gained the goal weight at almost every appointment and he is the tallest in his class! This is due to the treatment of shakes, vitamins, nutrition guidance, chest therapy/breathing exercises, and a combination of his incredible team of doctors, nurses, social workers, and dieticians at CCMC since day one. Not to mention our care at home due to the education we have received regarding CF at his birth. Early intervention has allowed us, and him, to fight his battle way before CF rears its ugly head, suppressing it and slowing down the process. He has had many colds, infections, just like any other child without CF, but he bounces back because he has been on his treatments since his birth making him stronger and more resistant. Otherwise, Colby would not be doing as well. Can you imagine your child sick with a disease that, if simply screened at birth, could have given your child a better chance? How would you feel? You would question why you didn't know. You would wish to God that you knew and that he or she had that time back and were on treatments from day one buying years of life. Early diagnosis is the factor in their survival. These babies cannot take care of themselves, nevertheless speak up for their lives. We can do that for them and we should. That is our job as parents, family, a community and government. Screening newborns for CF can prevent so many health problems, heartache, and time wasted and extend their lives by years! If it were your child having a life threatening disease, would you do anything in your power to add years to their life? Please pass Bill *House Bill 6263, An Act Requiring The Administration Of A Screening Test For Cystic Fibrosis To Newborn Infants*. It will make a difference for these babies. A simple test for a longer life.